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REVIEW OF FURTHER DEVELOPMENTS IN FIELDS WITH WHICH THE SUB-COMMISSION HAS BEEN OR MAY BE CONCERNED

Potentially adverse consequences of scientific progress and its applications for the integrity, dignity and human rights of the individual

Working paper prepared by Mr. Osman El-Hajjé in conformity with Sub-Commission decision 1996/110

Introduction

1. The author hopes he may contribute to the consolidation and promotion of the human rights and dignity of the individual by demonstrating that beneficial, fertile coexistence between the advances of science and technology and the human rights and dignity of the individual is both possible and desirable. In this respect, science has to be, and is, in the service of humankind.

2. Taking the international community's current concerns regarding the undesirable effects of advances in science and technology as his starting point, the author has tried to identify points on which agreement has by now been reached. He has also drawn on other writings on the subject to draw attention to the gaps in international legislation and to propose a way of making them good.

3. Advances in science and technology have been and are being initiated by man, a being equipped with the ability to reason, to deduce, to structure his thoughts, to accumulate knowledge and to draw conclusions. These advances have given him the means of overcoming obstacles, of broadening his horizon, of discovering the infinitely small and of stretching his hopes in all directions towards the impossible.

4. Thus man, who used to believe in the power of objects and to worship them, discovered thanks to his scientific and technical progress that objects on their own are inert and infertile, and that abilities, skills and procreation are man's attributes, and that by implementing and developing his own science and his own technology, he can derive the greatest benefit, not only for himself, but also for the whole of the society in which he lives. He reached the conclusion that the quality of sacredness belongs not to objects, but to man, who can create, invent and change objects and other living beings, or make them disappear. Some went as far as to say that the technology invented by man "achieves what divine intervention achieved in nature and human intervention in history." 1/

5. Starting from that premise, man, in order to pursue his creative and innovatory activity, had to set out to conquer and enjoy freedom, security and dignity, which were all indispensable if he was to complete the task he had begun when he was born on earth and whose end and fulfilment may not be foreseen. Man therefore had to acquire the rights inherent in his own person, namely the rights to life and to physical integrity.

6. This set of rights and freedoms came to be recognized and officialized in the Universal Declaration of Human Rights (art. 3) and the two International Covenants, on Civil and Political Rights (art. 6) and on Economic, Social and Cultural Rights (art. 12). To this recognition was added the prohibition of discrimination between persons on the grounds of race, colour, sex, language, religion, opinion, national, ethnic or social origin, property at birth or any other reason, as well as the prohibition of all forms of discrimination against women and enhanced protection for the child and the human embryo.

7. However - and this has been incontrovertibly demonstrated by history, and even very recently - on the one hand advances in science and technology can rebound adversely against man, if they are used for purposes other than those intended, and on the other hand man cannot be left alone with science and technology without trying to go further than what is good for him. Under the influence of his success, his illusions, his passions or his inflated pride, man is capable of taking an irreparable step, destroying his life and his very existence with the very science and technology he himself invented.

8. In order to lessen or eliminate such a risk, and the dangers underlying scientific and technical advances, man in his wisdom has sought, at every stage of his development, to control himself by setting limits which are not to be exceeded and by establishing standards of conduct for all to follow. Thus, though it may be possible for him to be acquainted with everything and to possess all knowledge in the search to satisfy his very essence, man must not attempt to do everything, because he is not alone in bearing the consequences of his actions; these may harm both their perpetrator and others, which is unacceptable in view of the duty of each person to respect and to safeguard other people's rights. It is so because it is not the individual alone who decides, but all the persons who make up democratic society and ensure its survival and perpetuation through their activities, their efforts and their lucidity.

9. Then how can it be ensured that progress will not bring with it disaster or misfortune? The most suitable method would appear to be to supervise scientific activity, although this means preparing a list of research areas where advances may entail negative aspects which need to be remedied. The solution would be to surround scientific research with legal and material safeguards, while respecting scientists' rights to freedom and dignity. Such safeguards are desirable because society can and must have them for its own security, provided that progress is not thereby hampered.

I. RESEARCH AREAS WHICH MAY PRODUCE UNDESIRABLE EFFECTS

10. These areas do not lend themselves easily to classification. Scientific activity is extremely wide-ranging and encompasses all aspects of human life, from the time the embryo is conceived to the time a human being is born, lives and finally disappears or, to be less categorical, departs for a better world. There are some areas of activity, however, which appear more risky than others and which require constant attention: (a) medicine and health, (b) computing and (c) nuclear energy.

A. Medicine and health

11. The advances achieved in the fields of life and health sciences and the awareness of their human implications have marked the end of this century, at a time when man is able to combine his knowledge with the power to change the development of all species, including his own, by using the latest discoveries in genetics and embryology. In view of this, there is a need to ensure that scientific advances benefit humankind as a whole, without detracting from human rights.

12. Several types of activity may be concerned in this respect, such as medical assistance to procreation, transplants of human body parts, examinations of a person's genetic characteristics for the purposes of predictive medicine, therapies produced by genetic engineering and biomedical research into the human being. 2/ In recent years, some scientific advances have been misused, so that therapeutic techniques have been diverted to purposes which are not necessarily desirable. One such example is facilitating pregnancies in women beyond the natural age of procreation and the possible consequences of this practice for a child's parentage and rights. Similarly, marrow and tissue transplants cause conflicts of interest between patients awaiting a transplant and potential donors, dead or alive, and their families. Furthermore, serious doubts may be entertained regarding the use of predictive genetic tests with no therapeutic or preventive finality, especially in the course of medical examinations prior to job recruitment or to signing insurance contracts.

13. We may also add genetic applications in the area of prenatal or pre-implant diagnosis. In order to preserve the human species, it would be preferable surely to use gene therapy with caution, restricting it to somatic cells (body cells excluding germ cells), to the exclusion of germ cells (i.e. the cells used for sexual reproduction). Equally, recent genetic research leading to the creation of mammal clones gives rise to mixed feelings, since it raises questions not only about man's dignity, but also about his social ties. This type of research might create two types of

human being: the real one, if we can use such a term, and the clone, with all the consequences one may imagine. While the freedom of research and researchers should be sacrosanct, as an essential precondition of any scientific progress, it seems inconceivable that man himself should become a subject of experimentation, considering that any scientific progress in the field of medicine sooner or later implies the transfer of therapeutic testing to the human being. It would therefore appear necessary to assert the primacy of man over science when consideration is given to studies into the human embryo, man himself or his genome.

14. In other respects, it may be noted that the increasingly sophisticated technology involved in medicine, especially in hospitals, has had a dehumanizing effect. It would appear extremely important, then, to restore respect for a patient's person and dignity at the heart of medicine, by confirming his right to be as fully informed as possible and to respect for his privacy. For this purpose, due consideration must be given to the patient's free and lucid consent. Similarly, in the event of a transplant, the deceased donor must continue to be entitled to respect for his body and his dignity, just as the living donor, who should be protected against any kind of pressure. A real effort should therefore be made to ascertain the will of the deceased prior to any organ transplant; the wishes of the family are secondary in that respect.

15. Gene therapy, for which patients sometimes require care for long periods, also raises a problem. The question is to what extent a patient may freely suspend or withdraw from a course of treatment, in view of the fact that certain new therapies in the last few years have been known to carry risks, apart from the usual uncertainties related to treatments.

16. In other respects - as confirmed unfortunately by recent events - scientific and technical advances in the area of the environment and food have led to harmful consequences for public health (as in the case of mad cow or Creutzfeldt-Jakob disease).

B. Computing

17. The benefits of computing - as indeed those of medicine - are beyond any doubt. But this does not prevent the advances in computing from being usable, and being used, to the detriment of human rights and human dignity. The most flagrant evidence of this is the dominant position assumed by some languages, which try to propagate or to impose a particular culture and to marginalize and eventually eliminate other languages and cultures, through the latter's impoverishment and forced isolation. In this way, all differentiation, which is a source of enrichment, is precluded and the notion of a people and its corollary, solidarity, are dissolved, to be replaced by vague notions with no precise content or clear definition based on the concepts and ideas of the economically dominant and politically powerful people.

18. These harmful effects of advances in computing even invade the private lives of men and women by surreptitiously introducing an "outsider" in the family circle through networks and through the spread of information, which is either tainted and disrespectful of the rights of women and children

(pornography, paedophilia, cyber-casinos and games of chance), or which cannot be monitored, making it impossible to identify the person or persons responsible.

19. We may add that these advances also broaden the gap between rich countries equipped with computers and others which are not, with the effect that the latter's situation becomes further aggravated unless specific help is provided for them to catch up.

C. Atomic energy 3/

20. The production of energy from fissile material entails risks for human health and life and therefore jeopardizes all human rights by endangering individuals in their environment through the radioactive effects it can produce. Over-exposure to radiation destroys the body's immune system, heightens victims' vulnerability to infection and to different forms of cancer, and increases the occurrence of congenital malformations and psychological traumas. In addition, ionizing radiation can damage crops, the food chain, cattle, the marine ecosystem and in the last resort man, through the amount of iodine-131 which penetrates the body, mainly through cow's milk, and is concentrated in the thyroid gland, destroying tissue there and, after a period of latency, leading to cancer of the thyroid. To make matters worse, it is not easy to rid the body of this carcinogenic substance once it has been ingested. Similarly, exposure to the alpha radiation of plutonium produces chromosomal instability, which can be transmitted to offspring and can lead to the appearance of cancers in later generations or to mutations.

21. It therefore appears essential to make plans in good time for educating the public and for ascertaining the obligations of States in international law with regard to the effects of radiation resulting from the use of energy produced by nuclear fission.

22. Although the international community has already made substantial efforts, the risks involved have by no means been completely eliminated.

II. ETHICAL PRINCIPLES AND BASIC RULES

A. Freedom of scientific research

23. Scientific research must be left completely and totally free. Society may impose certain limits, however, based on its own ethical principles, without necessarily paralysing or inhibiting scientific research, which could lead to a country's loss of status. In this respect, scientific and professional associations play a leading role in determining the limits of this freedom by providing researchers with ethical principles.

B. Support for scientific research

24. The State cannot leave scientific research without material, financial and moral support. At the same time, contacts and consultations among scientists in all countries should be encouraged and supported, while reception facilities should be provided where there are none. A special

effort should be made by the international community for the scientists of developing countries in order to bring them in to research circuits and to fill the gap which continues to widen between them and the researchers of advanced countries. For this purpose, a support fund should be created for the benefit of research in the third world. Without such a fund, it will not be possible to stop the brain drain and the debilitation of the researchers' countries of origin, which will only have the effect of further widening the already considerable gap between them and the advanced countries.

C. Legal framework for scientific and technical activity

25. The international community has been aware of the harmful effects of the application of scientific and technical advances for some time. The International Conference on Human Rights, held in Tehran in 1968, sounded the alarm and the United Nations General Assembly subsequently adopted resolution 2450 (XXIII), in which it invited the Secretary-General and the executive heads of the competent specialized agencies to undertake a study of the problems in connection with human rights arising from developments in science and technology. The World Conference on Human Rights in Vienna in 1993 also raised the issue, as did WHO 4/ and UNESCO. 5/

26. The Nürnberg Code, laid down by the International Tribunal in its judgement of 19 and 20 August 1947, set out 10 rules to protect persons from medical experimentation undertaken as part of biomedical research. 6/ In 1992, the Council for International Organizations of Medical Sciences (CIOMS) adopted "International ethical guidelines for biomedical research involving human subjects". But while science may contain hidden dangers, it is also a source of benefits for humankind, which is why society takes a close interest in scientific activity and is not content generally to leave scientists alone in their ivory towers, free from any control or supervision aimed at limiting the potential dangers of their research and as far as possible guiding them towards the common good. But as Nicole Lenoir has said, "on one side excessive safeguards may hamper progress, while on the other side, practices which are dangerous for human health and freedom may become too commonplace". 7/

27. This having been said, the human being must be considered to be beyond and above any sort of material assessment and hence should never be used as a means, but should be looked upon as an end. This leads to a fundamental distinction between human beings and objects and to a categorical condemnation of slavery and anything resembling it, as well as of torture, and to respect for the embryo as human potential and a future human being. 8/

28. In this respect, a legal framework should ensure that the progress of science and technology benefits people without infringing their rights. In order to achieve this, a legal status should be determined for the human body, based on the prohibition of any trade related to the genetic heritage and the punishment of any act of a genetic character affecting any part or the whole of the human body. For this reason, all gifts of organs and tissues for therapeutic purposes should be subject to the prior, explicit written consent of the donor, which raises the question of the presumed consent of the deceased donor and the scope or validity of any authorization issues by the family or relatives. There is also the problem of protecting the individual

in the event of biomedical experimentation, in order to ensure that ethical principles are respected, namely respect for the integrity of persons participating in research, their free and lucid consent based on full information, after an assessment of the risks involved, in order to avoid any incident or undesirable effect, and lastly the duty of compensation in the event of accident. 9/ This means guaranteeing the confidentiality of personal medical data for the protection of privacy, respect for anonymity, and the assurance that research will not serve any other purposes than those for which consent was given.

29. It would therefore appear to be extremely important to promote legislative measures for the protection of personal data. At present, such protection is not guaranteed everywhere; nor is it suited to the need to protect medical secrecy. One may then legitimately ask how the confidentiality of medical and genetic data may be protected and what precautions should be taken to safeguard them; for instance, who should manage these data banks and for how long should data be preserved? Also, who should have access to them and under what conditions?

30. Research into human embryos and genomes also raises legal problems to which solutions must be found. For example, is it possible to patent DNA sequences and to label classified genes or to decide that a gene is defective without in fact infringing the human rights of the individual carrying those genes and without indulging in eugenics?

31. Lastly, is it possible to fill the gap there is at present between developed and third world countries if the benefits of science and technology in the area of genetic engineering and embryology are reserved for the advanced countries only? And the question arises as to whether, given the current state of science in the third world, it is possible for gene therapy to be used in those countries? What sort of promotion policy should be followed to enable developing countries to benefit from advances of science and technology in the field of genetic engineering?

III. RECOMMENDATIONS

32. The answers to all these questions can only come from the international community as a whole, through the drafting of universal legislation, which will safeguard cultural and religious specificities while ensuring the universal character of the protection of human rights and dignity. To achieve this, the international community, in addition to very active professional associations, should undertake the task as rapidly as possible of establishing a general framework of guidelines for researchers, establishing limits they should not transgress. Committees of ethics should be set up for the purpose in each country, in order to supervise scientific activity, to foresee possible excesses, to alert the authorities and public opinion and to act in an advisory capacity to assist public authorities as well as scientific researchers and their professional organizations. There would also be a need for an international committee on ethics. The members of such a committee should fulfil certain conditions as laid down either by the General Assembly or by the country of origin of the committee member.

33. The committee should be expected to draw up an annual report on the state of science and technology for submission to the General Assembly.

Notes

1/ Hannah Arendt, "Le concept de l'histoire, in La crise de la culture - Huit exercises de pensée politique, Paris, Gallimard, 1972, p. 79; Commentaire du livre de Giambattista Vico, La méthode des études de notre temps, Naples, 1908.

2/ The author would like to thank Professor Jean-François Girard, Director-General for Health in France, for his substantial contribution to this work. He would also like to thank WHO and UNESCO for their useful cooperation.

3/ See Herbert Abrams, "Chernobyl and the short-term medical effects of nuclear war", in Maintain Life on Earth, Acts of the Sixth World Congress of International Physicians for the Prevention of Nuclear War, Cologne (1986), 1987, pp. 122-125.

4/ In 1976, WHO published a study entitled "Health aspects of human rights with special reference to developments in biology and medicine".

5/ In 1993, UNESCO published a study prepared by Eugene B. Brody under the title "Biomedical Technology and Human Rights".

6/ Claire Ambroselli, "L'éthique médicale", Collection "Que sais-je?", Presses universitaires de France, Paris, 1988, pp. 103-107.

7/ Nicole Lenoir, "Les Etats et le droit de la bioéthique", Revue de droit sanitaire et social, 31 (2), 1995, p. 274.

8/ See Sonia Le Bris, "Les organisations internationales et la médecine moderne. Promotion ou protection des droits de la personne", in Les droits de la personne et les enjeux de la médecine moderne, Sainte-Foy, Presses de l'Université Laval, 1996, pp. 17-42.

9/ See "Bioethics and its implication worldwide for human rights protection", document of the 93rd UNESCO Inter-Parliamentary Conference, Madrid, 27 March-1 April 1995 (CONF/93/4-Doc. Inf. 1).